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The Socio-Genetic Marginalization in Asia Programme (SMAP)



SMAP, the Socio-genetic Marginalization in Asia Programme, which started off in August 2004, is a research programme set up with the support of the Netherlands Science Organisation (NWO), IIAS, and the Amsterdam School for Social Science Research (ASSR). Exploring cultural, social and economic aspects of the role of genetic technologies played in the area of state organisation, population policies, health care systems and research regulation in China, India and Japan, SMAP is expected to shed light on how differences in the application of modern genetic technologies generate different practices. The programme focuses on: (I) the ways in which (universal) regulation for genetic sampling by international companies and universities leads to disputable research practices among vulnerable populations; (II) how bioethical differences between healthcare systems are expressed in the different meanings allocated to concepts, such as informed consent, health, and family values; and, (III) the consequences of development priorities and practices of genetic screening for the livelihood and identities of diverging social groups.

Margaret Sleeboom-Faulkner

Asia boasts the main economic players of the 21st century. China, India and Japan especially will play main roles in the field of science, particularly in applied modern technologies. The concept of socio-genetic marginalization, which is central to SMAP, draws attention to the consequences of the practice of relating the social to the (assumed) genetic make-up of people, regardless of the relevance of such connections. Central are the socio-cultural and financial consequences of the use of genetic information. The projects of SMAP are conceptualised through three empirical research projects outlined below.

Genomics, population-policies and local traditions

Governments in China, India, Japan and Europe treat issues of population planning with various levels of importance and apply different political strategies. In China the issue of the new eugenics, the quality of the population and one-child birth policy are of great political and human significance. The one-child policy, widely practised since the late-1970s, in combination with a preference for males, has led to a lopsided growth of the population. By legal prohibition the state has tried to interfere against these practices, but as yet not successfully. In India, too, sterilisation, infanticide and prenatal gender discrimination followed by abortion have led to a population imbalance, in which the state tries to interfere. Japan and Europe, on the other hand, struggle with the problem of ageing population and falling levels of fertility.

Thus, a variety of genetic technologies are available to the state in policies aimed at raising the quality of the population. Such population policies are part of an attempt to 'improve' the genetic composition of individuals or entire peoples. The 1995 introduction of the new eugenic legislation in China, for example, supports the systematic 'implementation of premarital medical check-ups' on hereditary, venereal or reproductive disorders as well as mental disorders so as to prevent 'inferior births' (Ministry of Public Health, 1994). A different tendency can be found in the Netherlands, where members of the medical profession observe that the state is obstructing their duty of providing all possible information and alternative treatment to patients by not allowing them to practice pre-embryo-screening and prenatal genetic research.

There is a need for the comparison of clashes of state population policies with local traditions in India, China, and Japan. Modern technologies of genetic engineering increasingly allow the government to intervene and regulate the personal lives of individuals in the name of public health, religion and national good. Concomitantly, concepts of health and human values in society are likely to be influenced. However, in some cultural environments, such as in India, it is the state that tries to put a brake onto the prenatal gender selection of its population.

Genetic sampling and vulnerable groupings in genetic sampling sites

The twofold aims of this project are, first, to understand the socioeconomic and cultural conditions of genetic sampling and banking in isolated areas and among ethnic minorities in different national contexts and, second, to the ways in which research populations are defined and mapped by researchers. The DNA of these socially defined groups is the subject of research in evolutionary genetics, the study of human reactions to various pharmaceutical products (pharmacogenetics), and the study of single nucleotide polymorphism (SNPs). Two kinds of issues are central to this research. The first involves the bioethical aspects of sampling and storing DNA. Current bioethical protocols still fail to deal adequately with the spe-

cific conditions raised by population-based research, in particular regarding procedures for group decision-making and cultural divergence (MST & MPH 1998; ICMR 2000). The second involves problems inherent in the ways geneticists define sample populations in genetic research. Before the sampling of populations begins, estimates are made about the genetic nature of target populations. The contents of these estimates are intimately related to historical processes of ethnic group formation, the intricacies of cultural perception and political interests.

In India, China and Taiwan, the DNA of various minority groups with suspect unique DNA are exploited commercially by research groups abroad and at home. This has caused considerable local, national and international strain. In Yunnan in Southwest China, ethnic DNA of over 25 so-called national minorities is stored in the world's largest ethnic databank in Kunming (*People's Daily*, 22/11/00). Such research is used to support claims on ethnic and national identity and to resolve conflict over national territory. Bio-anthropological research from South India served to provide genetic evidence for the similarity between high caste Indians and Europeans (Bamshad 2001). In Japan and China similar population research attempts to 'scientifically' root the modern nation into venerable historical origins.

Genomics, sociogenetic identities and health strategies in China, India and Japan

Though increased genetic information means a step forward in predicting and curing genetic diseases, policy-makers also attempt to use it strategically to improve human populations and eliminate 'defective' phenotypes. In the private sphere parallel developments are taking place: early prenatal testing has motivated couples with an increased risk of affected offspring to have children, but the diagnosis of disorders has also led to a steep increase of selective abortion. A central question here is if and when we can speak of a link between national health care policy, public debate and the private sphere. For instance, in China the government started a one-child family-planning programme in the 1970s to ensure sufficient nutrition for all new-borns, which resulted in a substantially decreased birth rate. At the same time, this policy limits individual freedom and autonomy. On the other hand, infant mortality in China by the 1990s had become considerably lower than in India. The criteria for the cost-effectiveness of clinical genetics in developing countries are not the same as in wealthy countries, such as Japan, Singapore and Taiwan. In developing countries the severely handicapped do not usually survive and, if they do, they are not provided with expensive medical care. Consequently, the targets of genetics services are reached on the basis of a different balance sheet. Thus, in developing countries family planning, carrier testing, genetic counselling and prenatal diagnosis may have a different rationale.

Currently six researchers are working on SMAP. Focusing on reproductive genetic technologies (RGT's) and genetic counselling in Delhi and Mumbai in India, Dr Jyotsna Gupta studies how genetic screening affects the perception of genetic risk. To understand these processes, Gupta conducts fieldwork in hospital locations of diverging religious and socio-economic status. In her analysis, Gupta uses the categories of gender, religion, education and socio-economic status to understand the parental decisions made to abort or to carry the embryo to full term. At the same time, she relates her observations in these clinics to state-regulation, developments in the pharmaceutical industry and international bioethical guidelines and NGOs.

The application of RGTs in Japan and its effect on genetic selection after prenatal diagnosis and during pre-implantation genetic diagnosis (PGD) are central in the work of Dr Masae Kato. Her fieldwork focuses on the way parents make

decisions about their offspring in genetic counselling sessions, and the way government guidelines, medical institutions, the family and cultural-medical practices affect these decisions. Kato relates her findings to political and public debates on the socio-cultural value of the embryo, so as to understand processes of validating humans. Initially, Kato will compare the application of RGTs in Japan with those in the Netherlands, extending the comparison to the PRC next.

Interested in genetic sampling, screening and biobanking in India, Prasanna Patra studies medical policies on three tribes with high levels of sickle cell anaemia, whose socio-economic circumstances differ starkly, and investigates how screening affects the identity and health of the community. In general, Patra looks at what happens to genetic data and asks the following questions: who does the sampling and under what conditions? Where are the data stored and who has access to them? Patra aims to make sense of the various behaviours and motives of various interest groups, including academic researchers, pharmaceutical companies, state agencies, sampled communities and NGOs.

Two research students will start to work with us in September 2005. Suli Sui will conduct comparative research into the regulation of new genetic technologies regarding vulnerable populations. She reviews existing Chinese law in relation to gender, ethnic, and socio-economic status, after which she will compare similar issues in the context of regulation of genomics and society in India. Apart from weighing arguments in favour and against the universal regulation of biotechnology, she will offer recommendations on regulation that harm the interests of identified vulnerable populations.

The second research student, Jan-Eerik Leppanen, aims to understand the role of Chinese ethnic minorities in biobanking and hopes to gain a better understanding of the effects of the knowledge generated through genetic sampling. Apart from exploring how biobanking activities alter relations between ethnic groups and the state, and what commercial stakes are involved, this research tries to understand the social and cultural effects of these activities on the ethnic groups in question. <

Note

- 1 Single nucleotide polymorphisms or SNPs (pronounced 'snips') are DNA sequence variations that occur when a single nucleotide (A,T,C, or G) in the genome sequence is altered.

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